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# Adaptive Skills Training and Quality of Life of Young Adults with Autism

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Philadelphia College of Osteopathic Medicine

Department of Psychology

ADAPTIVE SKILLS TRAINING AND QUALITY OF LIFE OF YOUNG ADULTS  
WITH AUTISM

Reggie Candio, NCSP

Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Psychology

May 2019

PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE  
DEPARTMENT OF PSYCHOLOGY

**Dissertation Approval**

This is to certify that the thesis presented to us by \_\_\_\_\_  
on the \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_, in partial fulfillment of the  
requirements for the degree of Doctor of Psychology, has been examined and is  
acceptable in both scholarship and literary quality.

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## **Abstract**

The current study examines the effectiveness of a group-based adaptive skills training program in improving the perceived quality of life (QoL) of adolescents and adults with Autism Spectrum Disorder (ASD). The Adolescent and Young Adult Treatment Program (AYATP) is implemented by a specialized Autism outpatient treatment facility, with a focus on improving the personal independence and daily living skills of its participants. With the use of archival data from the specialized Autism outpatient treatment a study was conducted utilizing a mixed factorial design by analyzing pre- and post-measures of the participants' perceived quality of life, as measured by a research-based self-report questionnaire. The study also examined the relationship between quality of life ratings and lengths of treatment participation. The results supported the program's ability to improve overall participant quality of life ratings over the course of time. However, the hypothesized impact of program treatment experience on perceived quality of life ratings was not reinforced. Limitations in the amount of available outcome data for analysis may have impacted the generalizability of study findings to other racial, gender and disability groups with ASD. Overall, this study can be conceptualized as an initial examination of a unique treatment model, as well as a catalyst for future program evaluation aimed at improving treatment efficacy.

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## **Chapter 1: Introduction**

### **Introduction**

Despite the recent changes in the diagnostic guidelines for Autism Spectrum Disorder (ASD), the core symptoms continue to be described in terms of significant (atypical) impairments in areas of communication, social interaction and behavioral stereotypy (i.e., restrictive and repetitive behaviors and interests) (American Psychiatric Association, 2013). Although these symptoms are often initially identified in early childhood or during early school-age, symptoms typically persist throughout the lifespan (Shattuck, Abbeduto & Greenberg, 2004). Moreover, it is common to find some individuals with ASD suffering from comorbid medical, mental health and intellectual challenges, which further impacts their personal independence later in life (Roux et al., 2015).

ASD is a neurodevelopmental disorder that can significantly affect the quality of life of the individual diagnosed, as well as his or her close family members and caregivers (Schalock, 2000). Since its initial description in 1943 (Kanner, 1943), the prevalence rates for ASD has increased exponentially. In fact over the last few decades the occurrence rate has risen from 1 in 150 to 1 in 59 of the child population, with the highest prevalence rate seen among boys (CDC, 2014). Aside from the gender disparity observed in the epidemiological data, racial disproportionality in term of ASD prevalence and identification also exists because prevalence rates are higher for white children than for minority groups (CDC, 2014). Several theories have been posited by researchers regarding the cause of the observed upsurge in ASD prevalence rates, including the consideration of key factors such as biology, environment, changes in the way the

disorder is diagnosed as well as the way in which symptom patterns are reported and conceptualized (Hansen et al., 2015; Rosanoff et al., 2015).

The attainment of personal independence is a hallmark of transitioning to adulthood, but requires sufficient development of vital daily living skills in order to make the transition from child to adult successfully. Adaptive behaviors are defined as an individual's capability to be autonomous in everyday life through the use of communication, socialization, and independent-living skills (Kanne et al., 2011; Sparrow, Cicchetti, & Balla, 2005). Similar to individuals classified as having an intellectual disability, individuals with ASD may also present with impairments in adaptive functioning. However, differences in regard to severity level and functioning profiles exist between these groups (Bolte & Poustka, 2002; Kanne et al., 2011) because individuals with ASD are more likely to present with marked deficits in the social and communication domains of adaptive functioning (Kanne et al., 2011; Sparrow et al., 2005). Challenges with acquiring social and adaptive skills at a rate that is commensurate with normal development and their intellectual capacities, significantly impact the abilities of individuals with ASD to keep pace with the social and independent living expectations generally associated with adulthood (Flanagan et al., 2009; Kanne et al., 2011; Perry et al.). As a result, many individuals with ASD remain highly dependent on their families and available social supports to address their daily living needs (Ruble and Dalrymple, 1996; Howlin, 2000). Consequently, lack of competence in this crucial area of functioning leads to diminished opportunities for personal development and independence, thus hindering the realization of a quality adult life in the individual with ASD (Ruble and Dalrymple, 1996; Roux et al., 2015).

Quality of life is a complex construct that encompasses various elements related to a person's subjective view of his or her overall life satisfaction. These elements typically include a person's perceived level of functioning, autonomy, well-being, health, limitations (physical and/or psychological), social connections and sense of personal fulfillment in relation to one's environment and goals (World Health Organization Quality of Life Group: WHOQOL Group, 1998, p. 551). Individuals with ASD report significantly lower levels of quality of life compared with their non-disabled counterparts (Ruble and Dalrymple, 1996). Factors that typically predict higher levels of life satisfaction and better life outcomes for individuals with ASD are similar to the predictors applied to neurotypical individuals in the general population, including opportunities for gainful employment, healthy social relationships, and personal independence (Carr, 2014). Prior research on the topic of quality of life has made connections between this construct and an individual's adaptive functioning as it relates to independent skill mastery and participation in his or her community (Bigelow et al., 1982 p.350). Given this connection, effective adaptive skill training and life skills support can be seen as important elements in improving life outcomes for individuals with ASD (Roux et al., 2015).

### **Statement of the Problem**

Although a large body of evidence exists on the topic of social skills interventions and programming aimed at targeting the unique needs of children and adolescents with ASD (Laugeson, Frankel, Gantman, Dillon & Mogil, 2012), a huge void exists in the research in regard to supporting the adaptive needs of the adult ASD population (Matson, Hattier & Belva, 2012). This concern regarding the lack of evaluated interventions to

support the adaptive needs of adult with ASD has caught the attention of public health and human services organizations across the country (IACC, 2012). In addition to being a public health concern, there are huge economic stakes to consider because it relates to the need for effective transition programming and interventions for adults with ASD.

Coincidentally, the current cost of treatment and support for individuals with ASD throughout their lifespans has surpassed \$1.4 million per person in the United States alone and is nearly double (\$2.4 million per person) for individuals with comorbid intellectual disability (Buescher et al., 2014). Moreover, many adolescents and adults with ASD have poor educational and employment outcomes, which hinders their ability to contribute to their support costs and be fully integrated into their communities (Shattuck et al., 2012). Unfortunately, little research exists on efficacious interventions, strategies and programming that would help improve vocational, educational and community integration outcomes for adults with ASD (Hendricks & Wehman, 2010).

Despite this dearth of adaptive skill training research, a variety of evidence based-interventions have been identified (on their own) as viable practices in helping to improve the social and adaptive behavioral capabilities of adolescents and adults with ASD, including: applied behavioral analysis techniques, web-based instruction, direct instruction, task analysis and video modeling (Fonagy et al., 2015; Matson, Hattier, & Belva, 2012; McCoy et al., 2016; Otero, Schatz, Merrill, & Bellini, 2015). Although these practices and interventions have solid evidence behind their effectiveness in teaching discrete skills, the need for more knowledge regarding comprehensive methods and programming that promote adaptive skill development and generalization across environments is still a high priority (Hendricks & Wehman, 2010).

Adolescents and young adults with ASD who are classified under the Individuals with Disability Education Act (IDEA) as having the educational disability of Autism, typically receive specialized educational plans, accommodations/modifications, related services and transition supports aimed at promoting educational success in school (Missouri Autism Guidelines Initiative, 2012). However, individuals with ASD do not always receive the transition planning support for which they are federally eligible and are not always afforded the opportunity to participate in their own transition planning (Roux et al., 2015). Despite ASD being a lifelong condition, the school-based supports, related services (ex. speech-language therapy, occupational therapy, social work, case management, transportation and/or personal assistant services, etc.) and programming, that these individuals have come to rely on, will abruptly halt after they have fallen off the “service cliff” and have aged out of the educational system (Roux et al., 2015). Unfortunately, some adults with ASD struggle to obtain the services and supports that they need to improve their independent living skills and employability (Roux et al., 2015).

Following a call to action from parents of transition aged youth with ASD, in 2012 a specialized Autism outpatient treatment facility located in inner city Philadelphia developed a weekly adaptive skills training program, known as the Adolescent and Young Adult Treatment Program (AYATP). The program focuses on helping participants acquire independence in key areas of daily living. The treatment model incorporates direct skills instruction (through the use of adaptive skills curricula) with experiential learning activities and parent involvement, all within a relationship-based framework in an effort to promote better life outcomes. The integration of a multitude of research-based

approaches/practices, including ABA, relationship-based therapy and Cognitive Behavioral Therapy (CBT) to teach adaptive, social and vocational skills, makes the AYATP treatment model comprehensive and unique.

**Purpose of the Study**

The aim of this study will be to examine the effectiveness of the AYATP program, implemented by a specialized Autism outpatient treatment facility, as it relates to improving the perceived quality of life of adolescents and adults with ASD. A mixed factorial research design will be used to evaluate the effectiveness of treatment, specifically in terms of improving the perceived quality of life of program participants. Participant quality of life endorsements are considered a major outcome variable when considering the efficacy of the AYATP program, from the participant perspective. This information is also vital in terms of informing the course of treatment for participants, while reinforcing efforts toward self-advocacy. It is hypothesized that adaptive skills training provided through the AYATP program will lead to improved quality of life endorsements from adolescents and adults with ASD. Additionally, areas for program modifications and enhancements to best meet the needs of transition aged individuals with ASD will be explored, in order to support widespread use and replication of the program.

## **Chapter 2: Review of the Literature**

### **Introduction**

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by impairments in social interaction and social communication skill as well as the presence of restricted interests or repetitive patterns of behavior (APA, 2013). ASD is often referred to as a “spectrum disorder” due to the wide variability in symptom presentation seen among individuals diagnosed with this complex condition. In addition to the phenotypic heterogeneity observed among the population of individuals with ASD, variations exists in the amount of support needed to address the unique presentation levels of the disorder. These variations exist to the degree that the DSM-5 requires practitioners to ascribe a symptom severity level (e.g., Level 1= Requiring Support, Level 2= Requiring Substantial Support & Level 3= Requiring Very Substantial Support) when initially applying a diagnosis of ASD (APA, 2013).

### **Prevalence**

Since the introduction of this mystifying developmental impairment (seven and a half decades ago), the rate of children diagnosed with ASD is at an all-time high (now 1 in 59 of the child population are diagnosed with ASD) (CDC, 2018). This astonishing increase in prevalence rates has spawned several epidemiological studies aimed at uncovering the potential causal factors for this recent upsurge in new cases of ASD. One such study conducted by Hansen, Schendel and Parner examined the possible connection between increased ASD prevalence rates and recent changes to the diagnostic criteria for ASD, as well as the manner in which ASD cases are recorded and reported (Hansen, Schendel & Parner, 2015). To this end, the study reviewed Denmark public health data

for children born alive from 1980 to the end of medical follow-up in 2011. A stratified regression model was utilized to analyze the health records data and found that the change in diagnostic criteria had a broad effect on the prevalence rate of ASD, due to an observable increase in recorded ASD cases following changes in the diagnostic criteria in 1994. The study also found that the interaction between the inclusion of outpatient diagnostic records in the Denmark ASD registry and the changes in diagnostic criteria appeared to account for 60% of the increase in ASD cases recorded in the country. What the study also points out is the potential impact that increased awareness of ASD may have on the increased prevalence rates of ASD overall.

Currently, ASD prevalence data is substantially skewed toward the Caucasian male demographic, with disparately low identification numbers seen among females and minority groups (CDC, 2014). Although the gender difference in the ASD prevalence data has gone largely unexplained, the racial disparity between Caucasian and minority children in terms of ASD diagnosis has been linked to practical rather than genetic differences because diagnostic accuracy and the length of time before diagnosis are key factors in the epidemiological disparity observed between these group (Mandell, Listerud, Levy & Pinto-Martin, 2002).

### **Etiology**

Often tied to the topic of ASD prevalence rates is the etiology of the disorder. Given the significant rise in prevalence rates over the years, a great number of studies have been conducted and financial resources have been allocated toward uncovering the potential factors associated with the cause of ASD. Many of these studies have evaluated casual factors such as genetics, the environment and brain structure abnormalities during



development ([www.autism-society.org](http://www.autism-society.org)). Although a definitive cause of ASD has gone undiscovered, the relationship between or among the three aforementioned factors is widely accepted by the autism research community as viable causal elements (Belmonte et al., 2004; Inglese & Elder, 2009; Pelphrey, Adolphs, & Morris, 2004). It is likely that this strong early focus on disorder causation has influenced the rate at which other types of ASD research has been conducted over the years (including effective intervention, programming, support funding and adolescent and young adult outcomes) because etiology continues to be a prevailing emphasis in the realm of ASD research and will likely continue in that trajectory as new theories surrounding the origins of this disorder are posited (Inglese & Elder, 2009).

### **Diagnosis & Identification**

The identification of ASD can occur either in the clinical setting under the medical model or in the school setting guided by federal mandates related to public education. In either setting, the evaluative judgement of a credentialed and experienced practitioner, the utilization of specialized assessment measures, direct observations and input from caregivers and other relevant informants is required to diagnose or classify an individual with ASD. In the clinical realm, a diagnosis of ASD is typically made by licensed and experienced medical physicians (e.g., developmental pediatricians, psychiatrists, psychologists, etc.) who are trained to identify psychological conditions such as ASD (Missouri Autism Guidelines Initiative, 2012). In the school setting, ASD is not diagnosed; rather, it is classified as an educational disability under the Individuals with Disabilities Education Act (IDEA, 2004). Under this federal mandate, school aged students presenting with characteristics associated with ASD are evaluated by a school

psychologist to determine the relative presence of ASD as well as the student's need for specialized educational services. If the resulting evaluation affirms the presence of ASD related symptoms, then the educational classification of "Autism" is applied by the psychologist and the student's needs are programmed for accordingly (IDEA, 2004).

ASD has the reputation of being a challenging disorder to diagnose, given the variability seen in symptom presentation and its high comorbidity rate with other psychological conditions. As a result, a variety of specialized assessment measures, data sources and examination protocols are utilized to assist in making informed judgements related to the diagnosis and classification of ASD. In both the clinical and educational settings, direct observations, informant ratings on ASD specific rating scales and interviews are conducted as part of the evaluation process. Some practitioners (in either setting) may choose to utilize a standardized assessment tool created specifically to identify the presence of ASD symptoms such as the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2).

The ADOS-2 is widely viewed in the Autism field as the "gold-standard" assessment tool for measuring the core deficits of ASD across the life-span. The ADOS-2 utilizes a combination of semi-structured interviews, play-based observations examination and orchestrated social experimentation to assess an individual's social interaction skills, communication style, play skills, imagination as well as presentation of ASD related stereotypies, restrictive interest and repetitive behaviors (Lord, Rutter, DiLord, Risi, Gotham, & Bishop, 2012) . Regardless of which instrument is used in the identification process for ASD, practitioners in both settings reference the multiple

diagnostic criteria elucidated in the DSM-5 when making judgments about the presences of ASD.

Predating the most recent version of the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Editions (DSM-5), ASD was once identified as an umbrella disorder that encompassed several (yet separate) neurodevelopmental conditions that shared some common symptoms and were viewed as variations or subgroups of ASD, (APA, 2013). These ASD related, diagnosable conditions included Aspergers Disorder (AD) and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). However, following the release of the DSM-5 in 2013, these separate yet related conditions were subsumed under a single diagnostic classification now known as Autism Spectrum Disorder (APA, 2013). By re-conceptualizing the disorder as part of a spectrum of symptom presentation, some of the diagnostic overlap and ambiguities that frustrated parents and clinicians were seemingly addressed. In place of the separate diagnostic labels are levels of severity, which identify the amount of support the individual with ASD may need to function in daily life, as well as alternate descriptors that help to further clarify the diagnostic picture, specifically other comorbid mental health conditions or behavioral disorders (Ousley & Cermack, 2013).

### **Comorbidities**

Individuals with ASD present with a complex array of behavioral, adaptive and social-emotional challenges that impact their daily functioning to varying degrees. However, the co-occurrence of other medical and psychological conditions can further exacerbate presenting ASD symptoms. One such diagnosable condition that has been heavily tied to ASD is Intellectual Disability (ID). Although the ASD and ID comorbidity

rate has dropped over the years, from approximately 75% to roughly 38%, (CDC, 2014) Roux et al., 2015), public misconceptions about ASD and ID continue to link these two separate conditions together.

Roughly 65%-70% of individuals with ASD have also been diagnosed with some form of language impairment during their youth (Howlin, Savage, Moss, Tempier, & Rutter, 2014). These language impairments can range from the complete absence of verbal communication skills (non-verbal), delays in the development of appropriate receptive and expressive language skills, regressive loss of previous language skills within the first two years of life to pragmatic language deficits (e.g., difficulties with the appropriate use of vocal prosody, intonation, expressive body language, proxemics and conversational etiquette) (Howlin, Savage, Moss, Tempier, & Rutter, 2014; Weismer, Lord, & Esler, 2010). Similar to language impairments, Obsessive Compulsive Disorder (OCD) has been closely linked to ASD, due primarily to the shared characteristics of obsessive and perseverative thoughts as well as compulsive and ritualistic behaviors, which can be manifested in both conditions (Russell, Mataix-Cols, Anson, & Murphy 2005). Given their frequency of co-occurrence, some would argue that a diagnosis of OCD separate from OCD may be considered superfluous or redundant.

Attention Deficit Hyperactivity Disorder (ADHD) has the highest comorbidity rate with ASD when compared with other medical and mental health conditions. In fact, 53% of young adults with ASD also carry a diagnosis of ADHD (Roux et al., 2015). Similarly, an anxiety diagnosis is frequently paired with ASD; the co-occurrence rate is currently 51%. Moreover, due to associated social challenges, stereotyped behavior, perseverative tendencies, irritability and social isolation, individuals with ASD are at high risk for

developing a mood disorder, including depressions (Coleman, 2005). In fact, 24% of adolescents and young adults with ASD also have a diagnosis of Depression (Roux et al., 2015). Due to the existence of so many co-morbid psychological and medical conditions associated with ASD, the identification of an effective course of treatment (whether it be psychopharmacological, therapeutic or psychoeducational in nature) can be a daunting task.

### **Typical Treatments & Interventions**

ASD is considered a chronic neurodevelopmental disorder for which there is no cure or identified medical treatment that eliminates its core symptoms; rather, available ASD treatment has focused on symptom minimization and skill development aimed at improving the functional independence and quality of life of individuals suffering from ASD (Myers & Johnson, 2007). Although pharmacological intervention is also part of the treatment regime for some individuals with ASD, this course of treatment is primarily undertaken to address symptoms associated with co-occurring medical or mental health conditions (Myers & Johnson, 2007). In fact, 77% of youth with ASD are prescribed or are regularly taking at least some type of medication to ameliorate health related symptoms ((Roux et al., 2015). In many cases individuals with ASD are in need of services from all three intervention domains simultaneously as part of a combined treatment plan. Given the need for this level of comprehensive care management, the cost of treatment and educational programming for individuals with ASD is astronomically high from a monetary and resourcing standpoint. Unfortunately, this cost only increases as individuals with ASD move into adulthood (Ganz, 2007). Given the long term economical and societal implications associated with proper treatment and care for youth

and young adults with ASD, the need to identify and proliferate effective treatment models, programming and services has never been higher. To date, identified ASD related treatments and interventions fall under three major categories: Medical Management, Family Support and Educational Interventions, (Myers & Johnson, 2017).

Medical treatment for ASD has a solid research base and an effectiveness rate in addressing residual medical symptoms and comorbid conditions commonly seen within the ASD population. In this respect, symptoms such as; behavioral and attentional dysregulation, obsessive-compulsive symptoms, aggression, self-injury, sleep dysfunction, gastrointestinal difficulties, seizures, as well as anxiety and depressive symptoms are often the target of this mode of treatment (Myers & Johnson, 2017). Of the types of medications used to treat these co-occurring conditions, psychotropics are the most widely used with mixed reviews in terms of their effectiveness. However, the psychopharmacological research on the effectiveness of psychotropic medication in addressing symptoms that co-occur with ASD suggest that there is a sizable gap in the literature regarding the best approach to treatment management and guidance, as well as a reliable and quantifiable means of measuring the effectiveness of medicinal intervention for individuals with ASD (Myers & Johnson, 2017). As has long been accepted in the psychopathology research, effective treatment for individuals with a psychological condition often requires a multipronged approach that involves a combination of medicinal intervention, non-medicinal therapeutic approaches/treatments to promote skill building and the provision of environmental supports.

Family support is a vital element to the success of treatment and later outcomes for individuals with ASD, especially given the stress and emotional impact that families

of individuals with ASD experience as a result of supporting a disabled love one (National Research Council, 2001). With this consideration in mind, traditional approaches to family support such as family-based talk therapy, connections to support groups and shared resource networks and access to respite care and additional advocacy services are often prescribed by treating practitioners (Myers & Johnson, 2017). There has also been some support in the treatment literature for the use of sibling support groups to address the adjustment challenges that some siblings of individuals with ASD have experienced over time. Despite the support for this assortment of collateral services for families impacted by ASD, geographical differences in availability as well as how services are organized and funded in each state make access to these family supports a challenge for some families (Myers & Johnson, 2017). As a result, local educational agents and specialized mental health clinics are seen as the access hub for related service and support needs for individuals with ASD and for their families.

Under the educational interventions category, various research-based interventions and evidence based practices are employed in both school and therapeutic settings to address the skill deficits associated with ASD. These interventions and strategies can be provided a la carte as part of a focused, skill-based intervention or as part of a more intensive yet integrated comprehensive educational or treatment program. Regardless of the intensity, modality and setting where interventions are provided, the aim of these strategies is to improve the communication, social skills, behavioral regulation and adaptive functioning of individuals with ASD in an effort to improve personal independence and quality of life (Bregman, Zager & Gerdtz, 2005; Sarokoff & Taylor, 2001; Weiss & Harris, 2001). However, the research on effective comprehensive

programs and interventions aimed at improving the life course outcomes and life satisfaction of young adults with ASD is sparse and in need of further attention (Myers & Johnson, 2017).

### **Applied Behavioral Analysis**

Applied Behavioral Analysis (ABA) utilizes intervention approaches aimed at reducing the presence of competing behaviors while increasing the frequency of more desirable replacement behaviors over time (Simpson, 2001). Though not an intervention in its own right, ABA is a behavioral-based approach that encompasses many evidence-based techniques and practices that have been identified in the ASD literature as one of the most effective and established protocols for teaching and improving adaptive functioning in individuals with ASD over time (with or without a co-occurring intellectual disability) (Simpson, 2005). Of the ABA associated techniques used to improve the adaptive skill functioning of adolescents and young adults with ASD, error correction, reinforcement, feedback, written schedules, video modeling, task analysis, prompt hierarchies, modeling, self-management strategies and choice-making have been deemed most efficacious (Bellini & Akullian, 2007; Ganz & Sigafoos, 2005; Jerome et al., 2007; Watanabe & Sturmey, 2003). However, there is no current literature that examines the use of ABA principles in concert with other evidence based strategies to support the development of vital daily living skills of young adults with ASD.

### **Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)**

The TEACCH program model, a collaborative approach to skill development for individuals with ASD, involves close communication between the practitioner and parent,



careful crafting of a customized intervention plan and curricular approach based on the individual's strengths and needs. As part of the individual's program, structured teaching strategies, setting up the environment and activities to optimize successful acquisition of skills, the use of visuals and the promotion of independence from adult prompting are employed (Mesibov, 1997). Despite the wide spread use of the TEACCH program as a special education service offering in schools and in clinical settings, this specific intervention approach was found to be minimally effective in improving the communication and adaptive daily living skills of young adults with ASD (Virues-Ortega, Julio & Pastor-Barriuso, 2013). However, an extension of this research conducted by Linstead, Dixon, Hong, Burns, Novack and Granpeesheh (2017) found that intervention efficacy in the area of adaptive skills was moderated by treatment duration (length of treatment). This study also called for future research to examine the impact of treatment duration on the development of other adaptive skills and treatment outcomes for this group.

### **Development/Relationship-based Therapy Approach (DIR)**

The DIR intervention model is based on the early developmental bonding experience between parent and child during which early trust formation, skill building and behavior shaping occur (Prizant, Wetherby, & Rydell, 2000; Walton & Ingersoll, 2013). This approach much like ABA, incorporates various social intervention models that focus on building a relationship between the therapeutic practitioners and the child. This bond is built through trust, responsiveness to the interests, preferences and motivations of the child, which opens the door for skill teaching and learning. Other elements of DIR include: the view of the child as an active participant in the learning

process, routinely utilizing naturally motivating elements in the environment to support the emergence of specific social skills, the development of treatment goals that are individualized to the needs of the child, utilizing the child's interest as a mechanism in treatment and reinforcing the transactional process of learning (Prizant et al., 2000).

### **Transition to Adulthood**

The transition to adulthood is considered a period of time between ages 18 to 25, during which changes in age, development and cultural and institutional expectations around self-sufficiency and independence lead to shifts in an individual's self-concept, personal responsibility and priorities as these relate to making life shaping decisions (Arnett, 2000). This phase of life can be very difficult and tumultuous for most adolescents, but even more so for individuals with ASD (deFur & Pattob, 1999). What often makes this transition so difficult for individuals with ASD are the deficits in learning, communication, social functioning, behavioral regulation, executive functioning and comorbid mental health challenges that are typically associated with the disorder (Roux et al., 2015). Although some individuals with ASD do experience some level of measurable success in their transitions to adulthood, many struggle to find their footing as they navigate the worlds of work, post-secondary education, their communities and variable aspects of living as independent adults (Hendricks & Wehman, 2009).

### **Completing School**

The research on the academic achievement of individuals with ASD is scant. However the U.S. Department of Education reported that the number of high school-aged students with ASD who graduated with a diploma was low in comparison with their neurotypical peers (USDOE, 2008). For example, data from 2005-2006 showed that only

38 % of students with ASD graduated with at least a standard high school diploma (USDOE, 2008). The remaining 62% received either a certificate instead of a diploma, graduated based on Individualized Education Plan (IEP) goals or dropped out. The identified variables that contribute to lower graduation rates for individuals with ASD are often connected to lower academic performance among students with ASD. For instance, students with ASD (on average) demonstrate literacy and math skills that are 4-5 years behind their neurotypical counterparts, even when they have received instruction in the same general education environment (Myles & Simpson, 1998). In a study conducted by Wagner, Newman, Cameto and Levine (2006), in which the academic achievement and the present levels of functioning were assessed for disabled students ages 16-18 using subtest from norm references direct assessments (Woodcock-Johnson III), it was found that adolescents with ASD scored three standard deviations below the mean of their neurotypical peers in four key academic competency areas (science, math, language arts and social studies). Although a large number of individuals identified with ASD are eligible for and receive specialized educational supports and/or accommodations through the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act during their primary and secondary educational careers, their needs for academic and functional support and services often extend beyond their age of school eligibility at age 21 (Roux et al., 2015). Given that the purpose of these specialized services and accommodations are to assist students in their preparation for an educational career after high school, it is important to consider key post-secondary outcomes for this population of students.

**Post-secondary Education**

The transition from high school to postsecondary education (e.g., college or trade school) is viewed by most students as a normal, yet exciting pathway toward preparation for adulthood. However, this postsecondary option can be cumbersome and difficult to access for individuals with ASD. According to data presented in the National Autism Indicators Report (2015), only 36% of young adults with ASD ever attend a four-year college/university, two-year junior college or vocational training program after high school. In comparison, only individuals with an identified intellectual disability have lower levels of postsecondary education experience (Roux et al., 2015). This number is vastly different for their neurotypical peers, who are enrolling in postsecondary institutions of learning at a rate of 75% within the first few years of leaving high school (Roux et al., 2015). Although a myriad of factors may impact the postsecondary education enrollment numbers for individuals with ASD, level of impairment, communication skills, household income, race and the postsecondary educational experience of parents appeared to be key outcome variables in relation to this trend (Roux et al., 2015). As part of a longitudinal transition study aimed at gathering crucial outcome data for individuals with ASD as they transition to adult hood (known as NLTS2), The U.S. Department of Education sponsored a nationwide research survey that collected relevant outcome data from a sample of students with ASD (ages 13-16) and continued collection of that data from original participants over a 8 year period ([www.nlts2.sri.com](http://www.nlts2.sri.com)). From this data set, it was reported that prospective postsecondary education students with ASD who presented with little to no difficulties with reciprocal communication skills, had a higher likelihood of attending a postsecondary institution of

learning (Roux et al., 2015). Similarly, young adults with ASD whose household income was above the middle income bracket (\$50k to More than \$75k), who identified as Caucasian and whose parents had a postsecondary education were more likely to access postsecondary education themselves (Roux et al., 2015). Although the survey research data do indicate that a portion of the young adult ASD population is primed to access postsecondary education options, it does not go far enough in describing the graduation or postsecondary success rate of this population, which is an equally important outcome to consider.

Although it is well documented in the research that young adults with ASD are not enrolling in postsecondary educational institutions and work training programs at the same regularity as neurotypical peers and students with other disabling conditions (e.g., other health impaired, learning or language disabled only) (Wei, Yu, Shattuck, McCracken, & Blackorby, 2013), little research is available on the total number of individuals with ASD who actually complete a postsecondary degree program. However, as part of the 5<sup>th</sup> wave of interviews conducted as part of the NLTS2 longitudinal study, it was reported that 41 percent of respondents with ASD who were enrolled in a postsecondary education program (during the 8 year data collection period) graduated and completed their studies, but 31 percent ultimately dropped out of their postsecondary institution prior to completing their degree program (Newman et al., 2011). When considering these low postsecondary education outcomes for individuals with ASD, one cannot help but wonder what current barriers are influencing these outcomes.

There has been a long held belief by K-12 educational systems that individuals with ASD, specifically those who have been identified as high-functioning, have a high

likelihood of success once they have reached the postsecondary educational setting. However, the literature uncovers several barriers to postsecondary success for this marginalized group that seemingly contradict this notion. Gelber, Smith & Reichow (2014) conducted a meta-analysis of 20 research articles with the aim of uncovering information regarding evidence-based supports and practices for individuals with ASD attending college; they also gathered information about these individuals' college experiences as they relates to potential protective factors and obstacles to success. Although the meta-analysis ultimately determined that the available research on these topics were scant, the available research did several barriers to college success for students with ASD; these include: lack of classroom readiness, anxiety, depression, social isolation on campus, social/relational challenges with peers, dorm mates and professors, lack of adequate disability support, schedule and course load management difficulties, reduced disability self-disclosure, underdeveloped self-advocacy skills and deficits in executive and adaptive functioning (Gelber, Smith & Reichow, 2014).

Moreover, two experimental studies (Mason et al. 2012; Pugliese and White 2013) that examined the efficacy of two distinctive interventions (video-modeling and psycho-educational CBT approach) aimed at improving the social communication and problem-solving skills of college students with ASD were reviewed by Gelber et al, 2014. Despite the promising efficacy data presented by both studies, the reviewing authors ultimately determined that the single-subject design of both studies was problematic in terms of external validity and provided little guidance on what an effective, postsecondary support/intervention program should look like. What is clear is the need for more research on intervention programs and best practices in supporting

young adults with ASD in postsecondary education is crucial in helping to improve life outcomes for this group (Gelber et al., 2014). One outcome that is clearly tied to postsecondary success is employment, particularly given the wide employment and earning gap that exist between individuals with a postsecondary degree, certification or license versus individuals without these credentials. Coincidentally, this gap is even wider for individuals with ASD (Newman et al., 2011).

### **Employment Opportunities**

Employment has long been viewed as a primary element of adulthood and a conduit toward economic prosperity, personal independence, social connectivity and self-esteem (Levinson and Palmer 2005; Rogan, Grossi, and Gajewski 2002). In fact, gaining employment after secondary school is often the primary transition goal for any disabled student receiving school-based support under IDEA (Cameto, Levine, and Wagner 2004). However, the employment outcome data for individuals with ASD is underwhelming, because young adults with ASD had the lowest employment rate (58%) when compared with neurotypical peers and peers with other disabling conditions only (Roux et al., 2015). Even if employed, individuals with ASD were more likely to work part-time hours at jobs that paid a low working wage (Roux et al., 2015). Similar to the postsecondary outcome data, an individual's level of impairment, household income during his or her early 20s, including the person's race, were key employment predictors for this group; individuals with ASD who presented with limited or no impairments in social communication skills who identified as Caucasian and who came from middle to high income households were more likely to have viable employment experiences (Roux et al., 2015). These outcomes illustrate the devastatingly low number of young adults with ASD

who are unable to support their personal independence financially and contribute to their households.

Disability self-disclosure also played a role in the work experiences of individuals with ASD. In fact, employed individuals with ASD (70%) reported that their employers knew they had a disability (Roux et al., 2015). Despite this level of self-disclosure, only 39 percent of employees who disclosed their ASD diagnosis actually received the workplace accommodations and support they needed to be successful in that setting (Roux et al., 2015). This revelation would indicate that disclosure of disability and workplace accommodation needs are not enough to ensure occupational success for young adults with ASD.

For young adults with ASD, obtaining and maintaining gainful employment can be a considerable challenge (Engström, Ekström, & Emilsson, 2003). Although the research on this employment disparity is sparse, a survey study conducted by Muller, Schuler, Burton and Yates (2003), found that the process of applying for employment (resume writing, completion of job applications, phone communications and interviews), acclimatizing to new job related routines, functional communication and social interaction were identified as areas of considerable challenge for job seekers with ASD. Challenges in these key job seeking, attainment and retention areas are not surprising, given the adverse impact that core deficits in social, communication and adaptive functioning have on employability for this group (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Given these life course challenges, researchers have called for further investigation into intensive interventions and programs aimed at reducing this negative trend for young adults with ASD, so that they have the chance to become independent



members of society and more fully integrated into their communities Seltzer, Shattuck, Abbeduto, & Greenberg, 2004).

### **Community Participation**

Despite reaching the age of majority, few individuals with ASD are living independently without support. In fact, national outcome indicators show that only 19 percent of young adults in their 20s, who have ASD, have ever lived alone without the support and supervision of another adult or parental figure, as compared with 66 percent of the general population in the U.S. (Roux et al., 2015). This rate of independent living is the lowest among all other disabled groups and is further exacerbated by key individual factors. For example, level of impairment, household income and race are vital indicators; verbally fluent, middle to upper income (\$50k to more than \$75k a year), Caucasian young adults with ASD were more likely to have experienced living alone when compared with peers of dissimilar demographics (Roux et al., 2015).

When reviewing the literature on barriers to independent living for this population, the core deficits of ASD as well as underdeveloped adaptive and executive skills seem to account for the lion's share of the identified reasons for the failure to launch seen among this uniquely disabled group (Kanne, Gerber, Quirmbach, Sparrow, Cicchetti & Saulnier, 2011). Due to these functional deficits, young adults with ASD may have a difficult time adjusting to novel situations, to simultaneously processing complex pieces of information, solving daily problems, managing resources and planning ahead, which are key skills necessary for independent survival and community inclusion (Minschew, Meyer and Goldstein, 2002; Tsatsanis, 2005).

One area of daily functioning that may be taken for granted by individuals without developmental needs is community participation. As adults living in a given community, there are natural opportunities for social engagement and intermingling of one's life with that of others through daily interaction. These interactions can occur at work, at school or when visiting community business, running errands, attending community events and engaging in leisure activities in the community (movies, sports and recreation, jogging, etc.). Involvement in these daily social interactions also provides opportunities to expand social networks and possibly to encounter those peers in the community who share similar interests. Despite these valuable possibilities, one in three young adults with ASD experience limited community participation and one in four reported increased social isolation within a year of leaving high school (Roux et al., 2015). The rate of social isolation among young adults with ASD was significantly higher than any other disabled group (24%) (Roux et al., 2015). Protective factors within this group were seen among young Caucasian and African American adults with adequate to proficient social communication skills, were of middle to high socioeconomic status or lived with a parent or relative for a year out of high school (Roux et al., 2015). Several barriers to community inclusion and social connectedness have been identified in relation to this group of young adults with ASD, including; social skill deficits, the presences of stereotypical or challenging behaviors, communication difficulties and under-developed adaptive skills.

### **Personal & Social Relationships**

Transitioning to adulthood involves the fulfillment of several key life course experiences, including the development of strong social bonds as well as satisfactory

personal relationships. However, for many young adults with ASD, friendships, romantic relationships and social network building have been an elusive part of their lives for a long time, which is a circumstance that often does not improve through adolescence and into adulthood, regardless of the individual's level of functioning (Howlin et al., 2000; Orsmond et al., 2004). In fact, the core deficits of ASD and their presenting features are primarily responsible for the difficulties that young adults with ASD face in developing as well as maintaining strong interpersonal bonds and intimate relationships with others (Renty and Roeyers, 2007; Tarnai and Wolfe, 2008). Nevertheless, some adolescents and young adults with ASD are experiencing meaningful social relationships; this has spawned several studies examining factors that predict better relationship outcomes for this group. One such study was conducted by Orsmond, Krauss and Seltzer (2004), in which individual and environmental factors related to peer relationships and social activity engagement were examined in a sample of 235 adolescents and young adults with ASD who were residing at home with their parents. The individual factor involved personal elements such as age, gender and level of social interaction impairment; the environmental factor was related to (maternal participation in social and recreational activities, number of services received by the participant and level of inclusion in an integrated setting while in school. Family surveys, diagnostic interviews and behavioral inventories completed by the mother of each participant were utilized to gather data on study variables. Following a series of regression analyses, the study found that the prevalence of peer relationships was predicated by individual characteristics rather than by the characteristics of the environment. However, the environment paired with individual characteristics was predictive of a greater level of participation in social and

recreational activities. The study concluded that participants with greater adaptive functioning, social interaction skills, maternal social involvement and number of services received, inclusion experiences in school and low levels of externalizing behaviors were more likely to have friendships and participate in social as well as recreational activities in the community (Orsmond, Krauss & Seltzer, 2004). This also study brings to the forefront several implications from its research that supports the aims of this current study, including the need to obtain information directly from individuals with ASD regarding their perceptions on their own friendships and social satisfaction as well as the need for more intervention research geared toward improving the social connectedness of young adults with ASD (Orsmond, Krauss & Seltzer, 2004). The implications of this kind of program effectiveness research is crucial, given the importance of social relationships to an individual's overall quality of life (World Health Organization Quality of Life Group: WHOQOL Group, 1998, p. 551).

### **Quality of Life (QoL)**

Quality of life (QoL) refers to an individual's perceived level of overall life satisfaction (WHO; The WHOQOL Group, 1998). It is viewed as a multi-dimensional construct that encompasses several key components of an individual's life, including emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights (Schalock, 2000). Initially utilized by the medical field as a key consideration when evaluating the impact of disease and the treatment on a patient's overall life quality over time, QoL has been used more broadly as an outcome indicator in the psychological and

social-services fields, particularly with the ASD population (Kamio, Inada & Koyama, 2012).

### **QoL & ASD**

The literature on the quality of life of adults with ASD is still emerging. However, recent studies have examined several QoL variables within this population, including appraisal trends, predictors as well as factors related to QoL that are most salient to this group. For example, Jennes-Coussens, Magill-Evans and Koning (2006) examined the perceived quality of life of young men with and without ASD, utilizing the World Health Organizations' Quality of Life self-report measure. The study found that the ASD group expressed significantly lower levels of social and physical quality of life and had fewer positive employment experiences than their non-disabled counterparts. What this study delves into (at its essence) is the important life-course factors that impact the quality of life of adults with ASD. Carr (2014) takes this research a step further by examining key life-course factors (such as; employment, social involvement, communication ability, academic success, independence and sense of autonomy) on the QoL of young adults with ASD. The database study (which included the review and analyses of parent and youth interview data from 230 participants) found that employment, social involvement, communication skills and personal autonomy were the biggest predictors of higher QoL among this group. Although the study investigator expressed the value of this level of research into the QoL of individual's with ASD, the need for future QoL research that primarily focuses on the self-perceptions of QoL was identified as a subject for future research.

**ASD and QoL Self-Reporting**

Although viewed as a very useful outcome to examine in the medical and social services fields, its instability over time as well, as the subjective and hierarchical nature of this construct, has made it challenging in terms of developing ways to measure QoL accurately, especially among disabled populations (Schalock, 2000). Due to the core deficits of Autism and their impact on the personal independence and functioning of individuals on the Autism Spectrum across settings (Wehman, Smith & Schall, 2009), parents and caregivers often serve the role of primary communicator and proxy for their children when reporting to medical professionals and educators. The inherent challenge with this dynamic overtime is that individuals on the Autism Spectrum struggle to develop their own voices and do not often have the opportunity to advocate for themselves. Shipman, Sheldrick and Perrin (2011) explore this very topic in their research study examining the reliability and validity of self-reports made by individuals with ASD about their quality of life (QoL). Aside from reviewing and analyzing participant perspectives utilizing a validated QoL measure, the study also compared the results with previously published normative data and against parents' ratings on similar assessment tools. Overall, the study found that adolescents with Autism can reliably and validly report on their quality of life in some manner. These findings provide very crucial data that has implications for assessing the outcomes of various Autism treatments and interventions and in terms of expanding the role of individuals on the Autism Spectrum in active research. Despite the presence of limitations in sample size and the presentative nature of the selected population, this study calls for replication of results with a focus on

more moderating variables, as well as the use of QoL as an outcome measure for health-care interventions and programs targeting this population of youth.

### **Chapter 3: Method**

#### **Overview**

The need for effective and viable interventions to improve the life course outcomes of adolescents and young adults with ASD is significant. With this in mind, the purpose of the present study will be to examine the effectiveness of an adaptive skills training program, implemented by a specialized ASD outpatient treatment center, relative to the improvement of the adaptive functioning and perceived quality of life of adolescents and young adults with ASD. The current study will examine the impact of the Adolescent and Young Adult Treatment Program (AYATP) through a within-subjects, repeated-measures research design by analyzing pre- and post-measures of the participants' perceived quality of life, as measured by a research-based questionnaire completed by program participants. It is hypothesized that participation in the AYATP program will lead to an improved sense of life satisfaction for adolescents and young adults with ASD. The relationship between quality of life ratings and lengths of treatment participation among participant groups will also be examined.

#### **Participants**

Sixty seven adolescent and young adult participants (Mean Age = 16.7 years, range 14 – 21 years; 5 females, 62 males) were enrolled in the AYATP Program throughout the 2017-2018 program year. Participants for this study were selected, based on the availability of a completed pre-test administration of the primary outcome measure (QOL Questionnaire) on the first day of the 2017-2018 program year; this involved 50 prospective study participants of the 67 enrolled in the program. Of the 50 prospective



study participants, 8 were missing a post-test QOL Questionnaire; 4 submitted an incomplete post-test QOL Questionnaire, and 4 were administratively discharged from the program prior to the administration of the post-test QOL Questionnaire. As a result, these participants were eliminated from the final study sample.

As a result, the final participant sample consisted of 34 adolescents and young adults (Mean Age = 16.4 years, SD = 1.9 years, range 14– 21 years; 5 females, 29 males) who were enrolled in the AYATP program throughout the 2017-2018 program year.

Participants in the study were also separated into two different groups (Rookies or Veterans) according to their initial program/treatment enrollment start date (e.g., prior to July of 2017 and on July of 2017).

Of the 34 participants in this study, 19 were in the ‘Veterans’ group (began receiving program treatment prior to July 2017) and 15 participants were in the ‘Rookie’ group (began receiving program treatment on or after July 2017). In terms of age distribution, 12 participants fell into the 14-15 age band; 13 participants fell into the 16-17 age band and 9 participants fell into the 18-21 age range. Within the sample, 73.5% of participants were identified as Black or African American; 17.6% were identified as White or Caucasian, and 8.8% were identified as Hispanic. The study sample demographics were representative of the AYATP Program population demographics. All study participants had a primary psychiatric diagnosis of Autism Spectrum Disorder. In terms of baseline adaptive ability, at the time of QOL Questionnaire Pre-Test administration, sample participants presented with an average Adaptive Behavior Composite (ABC) score of 75.5 (Sample ABC Range of 51-108), which is considered to be in the Moderately Low range of functioning (Sparrow, Cicchetti & Saulnier, 2016).

Despite the unavailability of socioeconomic data for study participants in the AYATP program, the treatment center's 2017 annual report specified that 70% of clients involved in at least one of the programs offered through the organization fell below the national poverty line.

The AYATP program attendance rate for participants ranged from 72% to 100% (Mean Percentage= 90.1%, SD = 8.7%) or between 26 to 36 treatment sessions. As part of the progress monitoring protocol for the AYATP program, individualized treatment goals were assigned to all participants and reviewed with participants and their parent/legal guardian every 12 weeks. Participant treatment goals also corresponded with the skills training module each participant would be exposed to during the 12 week treatment cycle. Of the 34 participants in this study, 29.4% had general goals related to improving their understanding of social relationships and matters regarding sexual health; 17.6% had goals to improve their peer social interaction skills; 14.7% had goals to improve their independence in self-care and hygiene; 14.7% had goals to improve their pre-vocational skills; 11.8% had goals to improve their independence in domestic and home-care skills, and 11.8% had goals to improve their levels of independence in community living.

Sample participant AYATP treatment duration/experience (measured by number of months in treatment) ranged from 12 total months to 72 total months, with the average time in AYATP treatment for the sample falling in at 29.7 total months. Treatment experience/duration did not take into account participation in other forms of treatment participants may have received prior to or in addition to the AYATP program.

**Inclusion/Exclusion Criteria**

Participants in this study met inclusionary criteria as a condition of their enrollment into the AYATP program. Program admissions criteria require all participants to (a) have an ASD diagnosis; (b) be between the ages of 14 and 21 years; (c) not have a comorbid diagnosis of severe, or profound intellectual disability; (d) be free of significant functional and medical limitations (e.g., ambulation, hearing, vision, eating/feeding, etc.); (e) be able to be safely maintained and supported by a program staff ratio of 1 staff to 3 clients; (f) demonstrate functional verbal language skills (e.g., spontaneous requests and comments, ability to follow verbal directions, and a reasonable degree of motivation to engage in program activities); (g) demonstrate foundational social skills (e.g., basic imitation skills, ability to attend to peers, and tolerance of groups of six to eight people); (h) display generally safe behavior (e.g., no physical aggression or self-injurious behaviors) basic self-regulation skills; (i) demonstrate minimal gross motor mastery; and (j) not pose as an elopement threat on facility grounds or when out in the surrounding community. In addition to program-specific criteria, participant selection was also based on the completion of two Quality of Life Questionnaires within the 2017-2018 program treatment year.

**Recruitment**

Due to the research design and the convenient nature of the recruitment process, the participant groups reflected a volunteer sample obtained in an inner-city community and therefore is not representative of the overall general population. Informed consent for this study was not obtained because the AYATP Program is a standard treatment offering at the Autism center, available to individuals who meet the program's inclusion criteria;

the data utilized for this study is archival in nature and was analyzed in an ad hoc fashion. Moreover, program treatment was not randomized or manipulated, and for the purposes of this program evaluation study, all sample data were de-identified.

### **Measures and Materials**

The Quality of Life Questionnaire (QOL.Q), developed by Schalock and Keith, is a 40-item rating scale designed to measure objectively the perceived quality of life of individuals with intellectual and developmental disabilities (Schalock & Keith, 1993). The QOL.Q was developed, based on a multifactorial model that identifies the three aspects of an individual's life experiences that influence his or her perceived quality of life, including the perceptions of significant others, objective life conditions and personal characteristics (Schalock & Keith, 1993). QOL.Q items are divided into 4 distinct domains/factors: Satisfaction (i.e., How satisfied a respondent feels he or she is with life); Competence/Productivity (i.e., How competent a respondent feels about his or her pre-vocational skills, work related productivity and activities of daily living); Empowerment/Independence (i.e., How independent and self-efficacious a respondent feels) and Social Belonging/Community Integration (i.e., How socially connected and integrated a respondent feels he or she is in the community) (Schalock & Keith, 1993). In each domain area, higher scores are an indication of greater levels of satisfaction and consequently, higher total scores on this measure indicate enhanced overall quality of life (Schalock & Keith, 1993). The QOL.Q uses a 3-point rating scale format (1 lowest to 3 highest) for responding to each item within a given domain and is individualized to each question (i.e., 1 = *usually or always*, 2 = *sometimes*, and 3 = *seldom or never*) and the total score (range of 40-120) can be derived by tallying the scores from the four domains

(Schalock & Keith, 1993). The QOL.Q is administered in survey format to the individual (self-report) or a designated proxy respondent (ex. parents, teachers, community support advocate and/or mental-health professional) (Schalock & Keith, 1993). If multiple respondents/raters complete the QOL.Q on behalf of the individual, the numerical endorsements of each rater is aggregated to generate a single multi-rater score for each domain as well as the total score (Schalock & Keith, 1993).

### **Research design**

As part of the normal course of treatment, all AYATP participants are required to have two QOL.Q survey forms completed. All of the QOL.Q survey forms are administered by the participant's specific clinician to gather information regarding the participant's perceived quality of life at that particular point and time. As part of an archival data study, QOL.Q survey responses (gathered during the 2017-2018 program treatment year) from each study participant was extricated for further analysis. A mixed factorial research design was used to evaluate the effectiveness of treatment (i.e., Adolescent and Young Adult Treatment Program). The independent variable for the study was the module-based adaptive skills instruction delivered through the Adolescent and Young Adult Treatment Program, and the dependent variable was the change in perceived quality of life measured through the two QOL.Q surveys. After the QOL.Q survey data were compiled by the program Assistant Director and securely submitted for review, the four domains measured by the QOL.Q (i.e., Satisfaction, Competence/Productivity, Empowerment/Independence and Social Belonging/Community Integration) along with the overall QOL.Q total score were analyzed and used as measures of participants' perceived quality of life. (See previous

section entitled Measures and Materials for a more detailed description of the QOL.Q) Statistical analyses consisted of a paired samples *t* test to analyze pre- and post-measures of the participants' perceived quality of life to evaluate program effectiveness in improving this outcome variable for program participants. In consideration of the potential impact that length of time in treatment may have on participants' self-reports surrounding perceived quality of life, a split-plot ANOVA was conducted to assess differences in program effectiveness in this area across two identified participant treatment groups (Rookies or Veterans; participants whose recorded initial treatment enrollment date is either prior to July of 2017 or on July of 2017).

### **Procedure**

The AYATP program is administered at two treatment facilities managed by the same clinical organization. The program is delivered to participants once per week on Saturdays, from 10:00 AM to 2:00 PM by clinical personnel employed by the treatment center. Treatment sessions are presented through a structured schedule that includes a combination of direct instruction, skills practice/demonstrations, practical inclusion experiences in the community (when applicable) and leisure socialization opportunities. The program is delivered year-round (beginning in July) and separated into four 12-week phases/treatment periods. At the end of each treatment period, participant progress is reviewed by the treatment team, which includes the participant, direct clinical staff, clinical support specialist, staff psychiatrist, outside treatment or social services professional working with a given participant, as well as parents and family members of the participant. During the treatment meeting, the team reviews several sources of data, including individualized treatment goal data, end of skill module practical assessment

performance, participant completed Quality of Life Questionnaire, and anecdotal or observational data from parents/family and clinical staff. The treatment team utilizes this data, along with input from treatment staff, family members and outside service providers, to determine how well the participant responded to treatment. In addition, potential barriers to progress (e.g., competing behaviors or skills deficits) are explored and necessary modifications to the participant's treatment plan are made. Last, the treatment planning process includes a discussion with the participant and family to identify discharge goals and to prepare for the transition out of the AYATP after the team determines that this level of care/support is no longer medically necessary.

In order to promote homogeneity with regard to skill area targeted in each individual's treatment plan (i.e., advanced social skill module, sexuality and relationships module, etc.), participants are enrolled in smaller treatment groups (i.e., one staff to three participants) where a specific topic or functional area is emphasized with the group throughout the treat period. Programming is facilitated in small groups by Bachelors and Master's-level clinicians (supervised by a clinical support specialist and assistant program director) who work closely with participants and make modifications/adaptions to curricular lessons to improve access and comprehension of presented material/skills.

Although the treatment center's clinical orientation is grounded in Relationship Based Interventions and the Developmental, Individual Difference, Relationship-based (DIR) treatment approach (also known as DIR Floor time Model), the AYATP utilizes elements of DIR identified as effective for use with the adolescent and young adult population on the Autism spectrum. In addition, facets of applied behavioral approaches, psychoeducation and best practices in teaching vital adaptive skills to individuals with

developmental disabilities are employed as part of the program's treatment model. As a result, adaptive behaviors are shaped, specific tasks are analyzed and organized, preplanned reinforcements are identified and thoughtfully applied.

The AYATP utilizes an eclectic module-based curriculum adapted from several sources including; UCLA's Program for the Education and Enrichment of Relational Skills, or PEERS ([Laugeson, 2014](#)), the YAI/National Institute for People with Disabilities Relationships Video Series (YAI, 2007), and the Functional Independence Skills Handbook: Assessment and Curriculum for Individuals with Developmental Disabilities (Killion, 2003) and the Asperger's Syndrome and Sexuality: From Adolescence through Adulthood Curriculum (Henault, 2006). In addition to the aforementioned curricular material, the AYATP employs various evidence-based approaches involved in teaching new skills to individuals with developmental challenges, including the use of task analysis, modeling/demonstration, role play, group discussion, and performance feedback, assessment of skill mastery, skills activities and self-appraisals.

In consideration of the ASD population the AYATP supports in treatment; each session has a similar format to promote predictability and continuity. Every program session includes a review of the learning objectives for the day, group discussion using prompts, and practical skill application experiences in an effort to transition participants from knowledge to practice. A summary of key skills covered during the entire module is also presented prior to the end of the module and a practical skills assessment is conducted to ensure mastery of the skills taught. Clinical staff facilitating groups are trained in all of the curricular content and are provided prescriptive facilitator guides to



ensure proper sequencing of skills topics throughout the treatment cycle. To support treatment progress monitoring, program clinicians collect data on each participant's individualized treatment goal, write progress notes for each session, proctor the end of cycle practical skills assessment and administer the QOL.Q survey to participants.

In terms of treatment fidelity, the Clinical Support Specialist (CSS) completes clinician review forms, conducts live observations of treatment groups via program room video feed, audits treatment progress notes and participant data sheets and provides clinical feedback during monthly team meetings. During team meetings, the status review form is used as the primary feedback mechanism. The information presented on this form is qualitative in nature (i.e., clinical summary, therapist collaboration, and group management), but is utilized to identify key concerns and factors that are influencing treatment fidelity. There is also a section of the form that highlight recommendations for improvement. The CSS provides observations in the clinical summary section (e.g., the skills the participant group is reviewing on that day, participant reactions to the group facilitators, and the techniques and strategies used to support skill development and participant treatment goals). The clinical summary also comprises information regarding skill activity and background knowledge delivery (e.g., sequence and delivery quality of didactic element of treatment). In addition, the therapist collaboration and group management sections of the form include information on how well the group facilitators worked together and addresses participant needs during the session (e.g., level of effective team work and collaboration demonstrated by the group facilitators, the roles each facilitator took on within the group, etc.). Following their completion, the status review forms are then dispersed to the Assistant Program Director,

reviewed further during supervision between the Clinical Support Specialist and Assistant Program Director before feedback is provided directly to the program facilitators during monthly team meetings. In the event that circumstances surrounding poor treatment fidelity arise, the clinical support specialist or assistant program director conduct follow-up observations within a defined period of time. At that time, further feedback is provided to the group facilitator, along with retraining with the clinical support specialist or the center's training department, if warranted.

During each 240 minutes treatment session, participants engage in various activities and exposure experiences that correspond with key adaptive skills needed to improve their personal independence. During each activity or segment of the program schedule, clinicians collect data to monitor participant progress toward individual treatment goals. During each 12-week treatment cycle roughly one lesson is presented to participant groups each week and clinicians conduct informal assessments of participant comprehension and retention of the presented skills along the way. If the facilitating clinician deems a specific skill to be in need of further explanation, repetition or modification in presentation for certain group members, time is taken to provide these accommodations in order to ensure that the entire treatment group progresses through the module at the same pace.

The AYATP program is designed in a manner that would allow each activity or time slot in the treatment schedule to address specific adaptive skills that are often underdeveloped in individuals with ASD. These skills vary, depending on the specific activity and module in which each participant is enrolled and include some the following skills: self-care and hygiene, domestic/home living skills, community use, relationship

and friendship building, sexual health and social interaction/communication skills.

AYATP treatment sessions are divided into seven time slots with corresponding activities to promote uniformly structured treatment sessions. First, from 10:00 a.m. to 10:15 a.m., group participants are transitioning into the treatment space and are expected to put away their belongings, assist in setting up the treatment space, finish their breakfasts (if they are still eating their breakfasts on their way into the facility), make initial selections for preferred job skills activity (to occur later in the session) and practice greeting and socializing with peers. Second, from 10:15 a.m. to 10:45 a.m., participants are oriented to the session agenda for the day, and skill objectives as well as participant expectations are presented. In addition, a review of skills and concepts covered during the previous session is conducted with the group to gauge retention as well to provide a logical bridge between skills. The third time slot, from 10:45 a.m. to 11:30 a.m., consists of providing participants an opportunity to practice the performance of vocational, domestic and community use skills with clinical supervision and support (ex. shopping, cleaning a mock bedroom, cooking lunch for the group). The fourth activity is lunch, from 11:30 a.m. to 12:15 p.m., during which participants are provided an opportunity to practice appropriate table manners while dining and interacting socially with their peers in a common social environment. During the fifth activity, from 12:15 p.m. to 12:45 p.m., participants engage in skill practice activities (ex. skill demonstrations, role-plays, video modeling review, etc.) to assist with further reinforcing the skill/topic concepts presented earlier in the session. The sixth activity, from 12:45 p.m. to 1:45 p.m., provides participants an activity to engage in recreational movement or interest-based leisure activities with peers. Last, the seventh time slot, from 1:45 p.m. to 2:00 p.m., was utilized

to deliver reinforcement or rewards earned during the session (ex. program dollars and purchases), as well as to give participants a chance to clean-up and reconfigure the clinical space, pack up and prepare for the transition home and say farewell to peers and treatment staff.

To monitor participant skill development and progress as well as gauge overall program effectiveness, four data sources are collected and utilized as part of the normal course of AYATP program treatment: the Vineland Adaptive Behavior Scale, Third Edition (VABS-3), the QOL Questionnaire as well as skill module practical assessment and treatment goal progress data. The Vineland-3 is an individually administered measure of adaptive behavior widely used to assess the communication, socialization and daily living skills of individuals with intellectual, developmental and other disabilities (Sparrow, Cicchetti & Saulnier, 2016). The Parent/Caregiver Form is administered to each participant's parent/guardian twice during the program year cycle (July 2017 and June 2018). The QOL Questionnaire is administered twice during the program year cycle (July 2017 and June 2018) by program clinicians in survey format to all participants. At the end of each 12 week treatment cycle, program clinicians administer an end of module summative practical assessment to each participant to measure his or her level of skill development and knowledge retention, relevant to the skill module he or she was presented with during the course of treatment. On this skill-based assessment, 80 percent mastery is required in order to be considered proficient and ready to move on to another skill module. In term of participant treatment goal data, each treatment plan includes one or two individualized treatment goals that coincide with the adaptive skill area in which each participant is working during the 12-week cycle. These goals are monitored during

each treatment session through data collection sheet completed by program clinicians. The data points on each participant's data sheet corresponds with the specific goal being assessed (e.g., frequency, duration, intensity) over the 12-week treatment period. In addition to the information presented in each participant's data sheet, clinicians provide an end of treatment cycle review of progress report, which includes a summary of participant goal data as well as anecdotal narratives that speak to observed participant strengths and needs, as well barriers to treatment progress and future considerations related to prospective goals, strategies and treatment interventions. All of the most recently collected treatment progress data for each participant is considered and incorporated into his or her treatment, before being presented to the participant and his or her parent/legal guardian during the treatment plan review meeting. See Table 1 for a summary of the evaluation methods imbedded within the AYATP discussed in this section.

Table 1

*Summary of Program-Imbedded Evaluation Methods*

| <i>Treatment Measure</i>      | <i>Construct Measured</i>          | <i>Frequency</i>              | <i>Assessor</i>               |
|-------------------------------|------------------------------------|-------------------------------|-------------------------------|
| <i>QOL.Q: Initial Probe</i>   | Perceived Life Satisfaction        | July 2017                     | Program Participant           |
| <i>QOL.Q: Second Probe</i>    | Perceived Life Satisfaction        | July 2018                     | Program Participant           |
| <i>VAB-3: Initial Probe</i>   | Adaptive Functioning               | July 2017                     | Parent of Program Participant |
| <i>VAB-3: Second Probe</i>    | Adaptive Functioning               | July 2018                     | Parent of Program Participant |
| <i>Treatment Plan Reviews</i> | Individual Treatment Goal Progress | Program Start Date; Every 120 | Treatment Team                |

|                               |                            |   |   |
|-------------------------------|----------------------------|---|---|
|                               |                            | Days  |   |
| <i>Skill-Based Assessment</i> | Module-based Skill Mastery | Session 12; Prior to End of Treatment Cycle | Clinician Facilitating Program Delivery |
| <i>Status Review Form</i>     | Treatment Fidelity         | Monthly                                     | Clinical Support Specialist             |

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Note. QOL.Q= Quality of Life Questionnaire, VAB-3=Vineland Adaptive Behavior Scale, Third Edition

## Chapter 4: Results

### Overview

In order to examine the hypothesis, “Will participation in the AYATP program lead to increased levels of overall life satisfaction, from the participant perspective?”, a split-plot (mixed factorial) ANOVA was conducted to compare study participant quality of life endorsements on the QOL.Q. The QOL.Q produces a Total Score, which denotes overall participant life satisfaction ratings as well as rating scores for each sub-domain assessed by the measure (i.e., Satisfaction, Competence/Productivity, Empowerment/Independence and Social Belonging/Community Integration). The dependent variables in this analysis was the QOL.Q rating scores, and the within subjects independent variable was ‘time’ (pre to post treatment). Given the fact that no incomplete or missing data was found in the data set, all 34 study participants were included in the analysis. The simple main effect of time was significant for the difference seen in sample participant quality of life ratings based on the QOL.Q Total Score, following a full program year of treatment  $F(1,32)=11.067$ ,  $p<0.005$ . Based on a sample size of 34, there was a significant difference between the mean scores for pre-test and post-test self-report endorsement total scores on the QOL.Q, where total post-test total scores ( $M=81.88$ ,  $SD=12.09$ ) were higher than total pre-test scores ( $M=76.59$ ,  $SD=7.98$ ), which indicates that study participants endorsed higher levels of overall quality of life post-treatment than they did prior to the start of treatment.

Similarly, The simple main effect of time was significant for the difference seen in sample participant quality of life ratings on the Competence/Productivity sub-domain of the QOL.Q,  $F(1,32)=13.391$ ,  $p<0.005$ , but not for the Satisfaction,  $F(1,32)=1.029$ ,

$p=0.318$ , Empowerment/Independence,  $F(1,32)=.136$ ,  $p=0.715$  and Social Belonging/Community Integration sub-domains,  $F(1,32)=.912$ ,  $p=0.347$ , which indicates that study participants felt more content with their levels of competence in the areas of pre-vocational skills, work related productivity and activities of daily living following the treatment period than they did in the other areas of life satisfaction assessed by the QOL.Q. (See Table 2 for additional statistics.)

Table 2

*Pre and Post Quality of Life Questionnaire ANOVA*

| QOL.Q measure                                | Pretest mean<br>(SD) | Posttest mean<br>(SD) | <i>F</i> | Significance |
|--|----------------------|-----------------------|----------|--------------|
| Total Score                                  | 76.59 (7.98)         | 81.88 (12.09)         | 11.067   | $p<0.005$    |
| Satisfaction                                 | 22.32 (2.60)         | 23.03 (3.39)          | 1.029    | $p=0.318$    |
| Competence/Productivity                      | 13.03 (1.73)         | 16.32 (6.19)          | 13.391   | $p<0.005$    |
| Empowerment/Independence                     | 21.32 (3.46)         | 21.68 (3.62)          | .136     | $p=0.715$    |
| Social<br>Belonging/Community<br>Integration | 19.91 (3.87)         | 20.85 (3.90)          | .912     | $p=0.347$    |

To examine the second research hypothesis regarding whether prior treatment experience in the AYATP program would lead to improved quality of life ratings between two different treatment experience groups (i.e., Rookies and Veterans), a split-plot (mixed factorial) ANOVA was also conducted on participants' pre- and post-treatment scores on the QOL.Q. It should be noted that all participants were included in



the analysis. An initial ANOVA of overall QOL.Q scores pre and post-treatment resulted in the identification of a main effect of treatment experience group on Total Scores,  $F(1,32)=11.967$ ,  $p<0.005$ , with participants in the Rookies group endorsing higher levels of overall life satisfaction pre and post treatment than the participants in the Veterans group. (See Table 3 for additional statistics).

Table 3

*Total Quality of Life Questionnaire Ratings Between-Subjects ANOVA*

| Group    | Pretest mean (SD) | Posttest mean (SD) | <i>F</i> | Significance |
|----------|-------------------|--------------------|----------|--------------|
| Rookies  | 82.33 (5.75)      | 86.80 (9.84)       | 11.967   | p<0.005      |
| Veterans | 72.05 (6.46)      | 78.00 (12.53)      |          |              |
| Combined | 76.59 (7.98)      | 81.88 (12.10)      |          |              |

Despite the assumption of sphericity being met (Mauchly's  $W = 1.0$ ), the ANOVA did not indicate a significant interaction effect between treatment experience level and QOL.Q Total Scores,  $F(1, 32) = 0.224$ ,  $p = 0.639$ , which indicates that no relationship was found between prior treatment experience and program efficacy in improving overall participant quality of life endorsements following a year of treatment. (See Table 4 for additional statistics).

Table 4

*Total Quality of Life Questionnaire Ratings Within-Subjects ANOVA*

| Group | Pretest mean (SD) | Posttest mean (SD) | <i>F</i> | Significance |
|-------|-------------------|--------------------|----------|--------------|
|-------|-------------------|--------------------|----------|--------------|

|          |              |               |      |         |
|----------|--------------|---------------|------|---------|
| Rookies  | 82.33 (5.75) | 86.80 (9.84)  | .224 | p=0.639 |
| Veterans | 72.05 (6.46) | 78.00 (12.53) |      |         |
| Combined | 76.59 (7.98) | 81.88 (12.10) |      |         |

In consideration of participant endorsements on questionnaire items that clustered under the life satisfaction factor, a main effect of treatment experience was found on Satisfaction sub-domain ratings,  $F(1,32)=18.166$   $p<0.005$ , as participants in the Rookies group endorsed higher levels of life satisfaction than participants in the Veterans group. (See Table 5 for additional statistics).

Table 5

*Satisfaction Quality of Life Questionnaire Ratings Between-Subjects ANOVA*

| Group    | Pretest mean (SD) | Posttest mean (SD) | <i>F</i> | Significance |
|----------|-------------------|--------------------|----------|--------------|
| Rookies  | 24.13 (1.89)      | 24.40 (1.68)       | 18.166   | p<0.005      |
| Veterans | 20.89 (2.18)      | 21.95 (4.02)       |          |              |
| Combined | 22.32 (2.60)      | 23.03 (3.40)       |          |              |

Although the assumption of sphericity was met (Mauchly's  $W = 1.0$ ), the ANOVA did not indicate a significant interaction effect between treatment experience and adaptive skill instruction on the Satisfaction QOL.Q sub-domain,  $F(1, 32) = 0.365$ ,  $p = 0.550$ , which indicates that no relationship was found between prior treatment experience and program efficacy in improving participant life satisfaction endorsements during the data lookback period.. (See Table 6 for additional statistics).

Table 6

*Satisfaction Quality of Life Questionnaire Ratings Within-Subjects ANOVA*

| Group    | Pretest mean (SD) | Posttest mean (SD) | <i>F</i> | Significance |
|----------|-------------------|--------------------|----------|--------------|
| Rookies  | 24.13 (1.89)      | 24.40 (1.68)       | .365     | p=0.550      |
| Veterans | 20.89 (2.18)      | 21.95 (4.02)       |          |              |
| Combined | 22.32 (2.60)      | 23.03 (3.40)       |          |              |

Similarly, participant endorsements on questionnaire items that clustered under the Empowerment/Independence dimension, a main effect of treatment experience was found within sub-domain ratings,  $F(1,32)=9.804$   $p<0.005$ ; participants in the Rookies group endorsed higher levels of self-efficacy and personal independence than participants in the Veterans group. (See Table 7 for additional statistics).

Table 7

*Empowerment/Independence Quality of Life Questionnaire Ratings Between-Subjects ANOVA*

| Group    | Pretest mean (SD) | Posttest mean (SD) | <i>F</i> | Significance |
|----------|-------------------|--------------------|----------|--------------|
| Rookies  | 23.47 (1.85)      | 22.73 (2.82)       | 9.804    | p<0.005      |
| Veterans | 19.63 (3.53)      | 20.84 (4.02)       |          |              |
| Combined | 21.32 (3.46)      | 21.68 (3.62)       |          |              |

Although the assumption of sphericity was met (Mauchly's  $W = 1.0$ ), the ANOVA did not indicate a significant interaction effect between treatment experience and adaptive skill instruction on the Empowerment/Independence QOL.Q sub-domain,  $F(1, 32) = 2.252$ ,  $p = 0.066$ , which indicates that no relationship was found between prior treatment

experience and program efficacy in improving participant levels of endorsed self-efficacy and personal independence during the data lookback period. (See Table 8 for additional statistics).

Table 8

*Empowerment/Independence Quality of Life Questionnaire Ratings Within-Subjects ANOVA*

| Group    | Pretest mean (SD) | Posttest mean (SD) | <i>F</i> | Significance |
|----------|-------------------|--------------------|----------|--------------|
| Rookies  | 23.47 (1.85)      | 22.73 (2.82)       | 2.252    | p = 0.066    |
| Veterans | 19.63 (3.53)      | 20.84 (4.02)       |          |              |
| Combined | 21.32 (3.46)      | 21.68 (3.62)       |          |              |

Sample participant endorsements on questionnaire items that clustered under the Competence/Productivity dimension yielded a non-significant effect of treatment experience on sub-domain ratings,  $F(1,32) = 2.820$   $p = 0.103$  because participants in the Rookies and Veterans groups endorsed similar levels of competence in the areas of pre-vocational skills, work related productivity and activities of daily living. (See Table 9 for additional statistics).

Table 9

*Competence/Productivity Quality of Life Questionnaire Ratings Between-Subjects ANOVA*

| Group    | Pretest mean (SD) | Posttest mean (SD) | <i>F</i> | Significance |
|----------|-------------------|--------------------|----------|--------------|
| Rookies  | 13.27 (.884)      | 18.33 (6.69)       | 2.820    | p = 0.103    |
| Veterans | 12.84 (2.19)      | 14.74 (5.43)       |          |              |
| Combined | 13.03 (1.73)      | 16.32 (6.19)       |          |              |

Similar to previous results, regardless of the assumption of sphericity being met (Mauchly's  $W = 1.0$ ), the ANOVA did not indicate a significant interaction effect between treatment experience and adaptive skill instruction on the Competence/Productivity QOL.Q sub-domain,  $F(1, 32) = 2.780$ ,  $p = 0.105$ , which indicates that no relationship was found between prior treatment experience and program efficacy in improving participant perceived competence in the areas of pre-vocational skills, work related productivity and activities of daily living during the data lookback period. (See Table 10 for additional statistics).

Table 10

*Competence/Productivity Quality of Life Questionnaire Ratings Within-Subjects ANOVA*

| Group    | Pretest mean (SD) | Posttest mean (SD) | <i>F</i> | Significance |
|----------|-------------------|--------------------|----------|--------------|
| Rookies  | 13.27 (.884)      | 18.33 (6.69)       | 2.780    | $p = 0.105$  |
| Veterans | 12.84 (2.19)      | 14.74 (5.43)       |          |              |
| Combined | 13.03 (1.73)      | 16.32 (6.19)       |          |              |

Congruent with previous results, sample participant endorsements on questionnaire items that clustered under the Social Belonging/Community Integration dimension yielded a non-significant effect of treatment experience on sub-domain ratings,  $F(1,32) = 3.405$ ,  $p = 0.074$  because participants in the Rookies and Veterans groups endorsed similar levels of social and community connectedness on the QOL.Q. (See Table 11 for additional statistics).

Table 11

*Social Belonging/Community Integration Quality of Life Questionnaire Ratings Between-*

*Subjects ANOVA*

| Group    | Pretest mean ( <i>SD</i> ) | Posttest mean ( <i>SD</i> ) | <i>F</i> | Significance |
|----------|----------------------------|-----------------------------|----------|--------------|
| Rookies  | 21.47 (3.16)               | 21.33 (3.35)                | 3.405    | p = 0.074    |
| Veterans | 18.68 (4.02)               | 20.47 (4.34)                |          |              |
| Combined | 19.91 (3.87)               | 20.85 (3.90)                |          |              |

Last, regardless of the assumption of sphericity being met (Mauchly's  $W = 1.0$ ), the ANOVA did not indicate a significant interaction effect between treatment experience and adaptive skill instruction on the Social Belonging/Community Integration QOL.Q sub-domain,  $F(1, 32) = 1.229$ ,  $p = 0.276$ , which indicates that no relationship was found between prior treatment experience and program efficacy in improving participant social and community connectedness ratings during the data lookback period. (See Table 12 for additional statistics).

Table 12

*Social Belonging/Community Integration Quality of Life Questionnaire Ratings Within-Subjects ANOVA*

| Group    | Pretest mean ( <i>SD</i> ) | Posttest mean ( <i>SD</i> ) | <i>F</i> | Significance |
|----------|----------------------------|-----------------------------|----------|--------------|
| Rookies  | 21.47 (3.16)               | 21.33 (3.35)                | 1.229    | p = 0.276    |
| Veterans | 18.68 (4.02)               | 20.47 (4.34)                |          |              |
| Combined | 19.91 (3.87)               | 20.85 (3.90)                |          |              |

## **Chapter 5: Discussion**

### **Summary of the Findings**

The primary aim of this study was to examine the efficacy of an adaptive skills training program in improving the perceived quality of life of AYATP participants with ASD. In consideration of initial hypotheses as well as current literature on prevalence, etiology, treatment and life course outcomes for adolescents and young adults with ASD, the findings of this research study are discussed thoroughly. Following an explication of the study findings, a review of study limitations, implications for clinical practice and program improvement as well as directions for future research will be presented. Although the results outline key findings related to program effectiveness and participant endorsements of increased levels of overall quality of life, these findings should be interpreted critically and with consideration of program related logistical limitations that impacted study data collection and analysis.

### **Program Effectiveness**

It was initially hypothesized that participation in the center-based adaptive skills training program would lead to improved quality of life ratings for adolescents and young adults with ASD. Following an analysis of archival treatment data related to the key study question, this hypothesis was supported. Within-subject analysis of study data found that direct adaptive skill instruction presented via the AYATP program resulted in increased endorsements of overall quality of life, as measured by a participant-rated quality of life measure (i.e., QOL.Q). Based on further within-subject analyses, the most significant improvement was found in the Competency/Productivity domain of the QOL.Q, in which participants rated themselves as presenting with an enhanced sense of

competence in their pre-vocational skills, work related productivity and ability to perform activities of daily living independently, following at least one year of treatment in the AYATP program. These findings are very encouraging, given the importance of employment and self-sufficiency to the overall quality of life of individuals with ASD (Carr, 2014). Although very limited research exists on the efficacy of adaptive skills training programs in improving the overall quality of life of individuals with ASD, prior research on the impact of this type of intervention has yielded complimentary results in terms of improved practical skills that are viewed as crucial for the acquisition of employment and overall job performance (Lattimore, Parsons & Reid, 2006). The current study also helps to highlight the need for further research on intervention protocols that meet the threshold for evidence-based practice and yield data that supports vital life course outcomes for individuals with ASD.

### **Effect of Treatment Experience**

This research study delved into another key inquiry regarding the efficacy of the AYATP program, specifically, whether or not treatment experience has an impact on the effectiveness of treatment, as measured by participant quality of life ratings. It was hypothesized that treatment history would influence quality of life ratings because participants with prior experience in the AYATP program (i.e., Veterans) would likely endorse higher levels of life satisfaction than participants who were entering the program for the first time (i.e., Rookies), due to their increased level of cumulative exposure to treatment conditions. However, following a review of the within-subjects data, this hypothesis was not supported; no relationship was found between treatment experience and quality of life ratings over time (even in subdomain areas). In fact, a between-



subjects analysis found that participants in the Rookies group endorsed higher levels of overall quality of life than participants from the sample with prior program treatment experience before the study look-back period. This difference between the groups was most prominent in the areas of overall life satisfaction, sense of empowerment and personal independence, but ratings on other QOL.Q sub-domains were analogous between the two groups. These findings appear to be incongruent with previous literature that supports the notion of a link between length of treatment and intervention efficacy for individuals with ASD, particularly in the area of adaptive skills (Linstead et al., 2017). Although there are several factors that may have led to the failure to reject the null hypothesis regarding the group by treatment efficacy relationship, one consideration is what the psychotherapy literature refers to as the dose-effect phenomenon, where the effect of therapeutic treatment is seen at its highest level during earlier sessions and slowly diminishes as the number of sessions/dosages increase (Kopta, 2003). With this phenomena in mind, the novelty of AYATP group treatment, the increased opportunities for peer engagement and interaction, and the exposure and acquisition of new adaptive skills may explain the reason why participants new to the AYATP program reported higher perceived gains in key areas of quality of life than participants who have been in treatment for a lengthier period of time.

**Limitations**

With consideration of the valuable findings presented in this study, particularly in regard to the viability of the AYATP program as an intervention that can yield positive outcomes for adolescents and young adults with ASD, it is important to consider key limitations that threatened the internal and external validity of this study. One such

limitation was the loss of participant data that ultimately led to a reduction in study sample size and outcome data available for analysis. Although the AYATP program had a census of 67 enrolled treatment participants at the start of the study lookback period (2017-218 program year), session absences on the days of pre and post administration of the QOL.Q, incomplete or incorrectly completed QOL.Q questionnaires and participant attrition (due to treatment related or administrative discharge prior to the end of the program year) reduced the sample pool by nearly fifty percent. This reduced sample size adversely influenced the statistical power of the study, which in turn jeopardized the significant relationships and findings yielded from the data analysis, as well as the generalizability of conclusions made to the broader population of adolescents and young adults with ASD.

Another potential threat to the generalizability of study results was related to sample demographics. Although, the gender distribution within the sample was considered congruent with the well documented epidemiological prevalence data for all individuals with ASD, the lack of female participants in the sample prohibited further examination and analysis of potential relationships between program treatment efficacy, life satisfaction ratings and gender. Moreover, the racial and socioeconomic make-up of study participants was not representative of the broader population of adolescents and young adults with Autism. The study sample was predominantly made up of individuals with ASD who identified as Black or African American, and a relatively small number of sample participants identified as Caucasian or Hispanic. In addition, based on the treatment center's 2017 annual report, the vast majority of individuals with ASD receiving treatment at the center were reported as living below the poverty line. With this

key participant characteristic mind, it would have been beneficial to have access to the actual socioeconomic status (SES) data for the sample so that correlations between participant SES and program efficiency related to quality of life could have been further examined. With this caveat in mind, study demographics were in alignment with the general make-up of the inner-city communities where the AYATP treatment facilities were located.

Another sample-related limitation was the lack of available data on the co-occurring psychiatric diagnoses that study participants may have had, in addition to ASD. These conditions along with the variety of subsequent treatments (both psychopharmacological and therapeutic) that participants may have accessed during the study data review period are important factors to consider, given their potential influence on the study outcome analysis of quality of life. Because the ASD population has such a high comorbidity rate, it would have been beneficial to have this data in order to conduct more between group analysis related to program effectiveness and specific comorbid conditions.

Direct correlations between treatment and life satisfaction outcomes were hindered by missing participant treatment progress data. For example, despite its being part of the normal treatment data collection protocol, data that provided information on the generalization and transfer of adaptive living skills outside of the treatment environment were not available for all study participants. This information is typically collected from the parent/guardian of each participant twice per treatment year, via the Vineland Adaptive Behavior Scale, Third Edition (VABS-3). However, it was reported by the AYATP Program Director that parent/caregiver compliance with completing the

VABS-3 has been a big challenge for some time and despite the implementation of online administrations of the VABS-3 to parent/caregiver respondents, completion rates have not improved. Moreover, the validity and reliability of parent/caregiver VABS-3 ratings have come into question in the past, due to the link between these ratings and continued eligibility for treatment services. For participants who received treatment or services sponsored by public health or managed care organizations, medical necessity in regard to treatment eligibility was connected to the level of functional severity derived from adaptive scales such as the VABS-3. This association often led to under-endorsement of participant gains by parents/caregivers in key areas of adaptive functioning.

Additional limitations of the study involved the timing of the QOL.Q pre and post intervention administrations. The characterization of the pre-intervention QOL.Q as a baseline measure is not truly accurate, given the fact that not all study participants began receiving treatment for the first time. Instead, some study participants have been enrolled in the program and have received treatment for 72 months prior the start of the study data lookback period. Although these participants were later grouped as “Veterans” and compared with sample participants who were truly assessed at the baseline level of their treatment (Rookies), it would have been beneficial to the overall study design had a true baseline assessment of participant quality of life been collected for all participants.

Given the fact that the intervention program was administered in a clinical setting, there were likely to be some logistical and programmatic idiosyncrasies that would inevitably influence the execution and scope of a quasi-experimental study of this degree. A key element of the AYATP program was the module-based structure of the adaptive skills training intervention. Program participants were enrolled in a treatment subgroup

based on a specific skill module with corresponding curriculum. Each module was meant to address the participant's unique adaptive needs and treatment goals. This diversity in treatment scope and curricular content exposure makes an overall evaluation of the AYATP program challenging. Last, in accordance with the aforementioned study design limitation, the center's primary theoretical model (DIR/Floortime) and its modified application with this population of adolescents and young adults with ASD is not considered evidence-based by peer-reviewed research standards (Mercer, 2017). This is an important factor to consider, despite the AYATP program's use of behavioral-based techniques, practices and strategies that have a strong evidence base within the ASD intervention literature.

### **Implications & Directions for Future Research**

Despite the threats to internal validity explicated in the limitations section, the findings of this study yielded support for the hypothesized notion that participation in a group-based adaptive skills program would help to improve the perceived quality of life of its participants significantly. Given reported challenges with collecting, storing and interpreting treatment outcome data related to program effectiveness in improving the adaptive skills of its participants, the development of a data collection plan that outlines the use of more reliable measures of treatment generalizability, as well as a more effective process for organizing and securing treatment outcome data for later use and analysis would be very beneficial for future program evaluation. The possible use of multiple types of data (ex. qualitative and quantitative), as well as multiple reliable informants (ex. parent, self-report and clinical staff) on rating measures that correspond with key treatment outcomes should be pondered. This is also an important clinical

implication because these measures would be considered the most impactful in terms of evaluating the sustainability and efficacy of the AYATP program model.

A stronger progress monitoring protocol would provide many benefits, including improved treatment planning, more accurate communication of participant strengths and needs, better identification of barriers to progress, enhanced therapeutic service delivery and treatment decision-making as well as better collaboration across the social systems supporting each participant. In addition, having strong outcomes to support the effectiveness of the AYATP program could lead both to expansion and to replication of the program model in other settings and regions/communities, which could help in the nationwide effort to reduce the gap between individuals with ASD and their neurotypical counterparts when it comes to important life-course outcomes. A program of this scope could also help ease the burden placed on local educational agency to meet the specific transitional needs of this population of uniquely disabled youth preparing for adulthood.

The present study attempted to draw a link between length of adaptive skill training and program efficacy in improving the perceived quality of life of AYATP participants, but failed to establish such a relationship. However, the study findings related to treatment dosage brought to light the need for future research aimed at examining what the optimal number of sessions should be for the AYATP program, in terms of identifying the level that is sufficient or good enough, relative to treatment efficacy/response.

The AYATP program's unique module-based treatment framework may require further refinement and definition, given the identified study limitations. However, future examination of program effectiveness by module would be beneficial in determining how

well the program is addressing the functional skill areas associated with each skill module and what curricular or implementation-based modifications may be required to enhance the development of a given adaptive skill throughout the course of treatment.

In consideration of the racial and socioeconomic makeup of the study sample, access to data from this unique population of adolescents and young adults with ASD (for the purposes of outcome research) is considered a rarity. This study provides a worthwhile opportunity to contribute to the already sparse literature on intervention efficacy for this underrepresented group of minorities with ASD. There are certainly cultural and socioeconomic considerations at play within this demographic that calls for further research that targets the life course areas most salient to this group.

The current study not only sought to examine the efficacy of the AYATP program in terms of improving life outcomes for individuals with ASD, but it also endeavored to add to the intervention research related to effective adaptive skill training programs for adolescents and young adults with ASD. With so much of the adaptive functioning literature geared toward youth and adults with Intellectual Disabilities (Klin et al., 2007), studies such as this are vital in making a case for further intervention research targeting this specialized population. With the rapidly growing number of individuals with ASD entering adulthood, the urgency to identify more evidence-based approaches, treatment programs and supports aimed at promoting the personal independence and community connectedness of this population has never been greater.

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